Northern Illinois University

Sharing Experiences of People with Disabilities

Department of
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Capstone Approval Page

Capstone Title (print or type)

Sharing Experiences of People with Disabilities

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Growing up with a brother who has disabilities has not always been easy. But I cannot imagine what life has been like for him, or anyone else who has a disability for that matter. Not many people realize what people with disabilities go through every single day of their lives. People with disabilities are often seen as being insignificant and irrelevant. This could not be more untrue. I wanted to work with Dr. Greg Long on this project to further this point.

When talking to Dr. Long, I found out his end goal was to make multiple short videos containing biographies or stories of people who have disabilities. My job, as part of the project, was to get to know multiple people who have disabilities and try to understand their thoughts and opinions of what they have to go through every day. After writing a narrative for each person, I then gave each an opportunity to be apart of the small videos that would later be produced. I was only able to do two interviews, but in my opinion one would have been enough of an eye opener.

Some individuals are born with disabilities, and some are acquired. Some are visible, and some are not. Disabilities are so wide in range it seems almost unlikely that a single person doesn't know someone with a disability. One would think that this would make it easier for people to talk about, but not talk down to, people with disabilities. This is not the case. There seems to be such a negative stigma that comes with having a mental disability. People are viewed as "crazy" or "insane" and because of this, it makes it that much harder for people to talk about. There shouldn't be anything negative associated with depression, anxiety, Asperger's, schizophrenia, or bipolar disorder. Those people are fighting their own battles with themselves, and shouldn't have to fight any other battle to get the help and support that they need. In hopes of spreading this idea, that is one of the reasons why I chose to do this project.

My first interview was with a young girl, Kalenna, who had been in a horrific car accident. She was on her way home from her orientation at NIU when a car came into the no passing zone and hit her and her mom head on. This is her story.

"Meeting and interviewing Kalenna was one of the most interesting and honest meetings I've ever had. Right away she was very open and willing to share her story with me, and I couldn't be more grateful for it. She was eighteen years old when she got into an almost fatal car accident with her mom. Another car that was going the opposite way crossed over and hit them head on. From the accident, Kalenna not only had a traumatic brain injury, but many other difficulties and surgeries. She has had 8 surgeries in six months that consisted of the removal of seven feet of her intestines, temporary colonoscopy, fixing a broken foot, repairing a broken fibula, placing a plate in two spots on her face because of broken bones, bone chips in her sinus passages, and many other problems.

Kalenna was in, what she had said, a "natural" coma for three days. Because of the extent of damage that was done, she was then placed in a medically induced coma to help her body repair and so her brain wouldn't swell. After many weeks in the hospital, she finally got to go home. No more than a week later did she end up back in the hospital for a blockage in her intestines. A nasal-gastric tube, which is when a tube is inserted into the nose all the way down the stomach, was put into place to get rid of the fluid in her stomach. She talks about how painful it was and that she couldn't eat or drink anything while it was in place. It was there for three weeks.

She finally got her surgery to remove the blockage. A supposed 12-14 hour surgery was only an hour and a half. I truly believe Kalenna had the best luck her in situation (not including the accident itself, of course). About sixth months later, she got her colonoscopy reversed and

she couldn't have been more excited. It was bad enough to have the stigma as having a TBI, but having a bag of poop always by your side isn't what any young girl wants.

The only times Kalenna talks about a bad encounter with a medical professional is when her first surgeon came and he and her family didn't get along. He didn't really show sympathy or any remorse for their situation and recovery process. But the more time spent with him, the closer all of them got. Now, she can't thank him enough for helping save her life. The other bad encounter would be when she had a psychiatrist who didn't seem to know what he was doing. He asked her the same few questions every day, and when she went to his office for a session and she starting crying, all he did was stare at her in shock like he didn't know what to do. That was the last time she ever saw him again.

I asked Kalenna if she ever thought of herself as having a disability. She said no, which is an answer I like to hear. She did have to go to physical therapy for the left side of her body because her TBI was on her right side of her brain. She describes her disability as being "slow-processing" which really is only apparent with her math skills. She also said her left leg will sometimes drag, but it's not noticeable to anyone who doesn't know her story. She does have accommodations for her classes, which consist of longer times for tests, getting the powerpoints from professors, and a talking calculator for math. She really doesn't need or use the accommodations she said and hasn't had any problems professors or teachers not understanding her situation.

An important part to her story involves her sex life. Many people do not think about the sexual needs and desires of people who have disabilities. In Kalenna's case, she may not be able to have sex ever again. The scar tissue from all her surgeries caused some of her sex organs to be fused together, making intercourse extremely painful and uncomfortable. She says that will still

be able to have kids later in life, and it will be with someone who is patient and who truly loves her, for her.

Nowadays, Kalenna enjoys being a freshman here at NIU and takes nothing for granted. She goes home frequently to visit and spend quality time with her family. She has an amazing support group of friends, family, nurses, doctors, and many others."

And after walking away from my interview with Kalenna, I couldn't help but talk to my boyfriend about it. I felt so lucky to be alive and finishing my fourth year at Northern Illinois University, and to have never experienced what her family did. I think what impacted me the most was her ability to talk so freely about everything that happened. She is very comfortable with herself and how she lives today. Her traumatic brain injury (or TBI) has definitely left its marks on her life, but that doesn't stop her from chasing her dreams in life. I was very grateful when Kalenna shared the intimate parts of her life with me. I know it couldn't have been easy at the time, going through multiple surgeries, watching her mother struggle to get better, being in a hospital for the better part of a year, and basically restarting her life. Her triumph and need for self-betterment have made her into what she is today. Her story was a true inspiration.

The second person I interviewed was Elisa. A bit older than Kalenna, Elisa has had her disabilities since she was young, but wasn't diagnosed until she was in twenties. She went through a lot to get where she is today and she still struggles with her invisible disabilities and confronts hardships head-on.

"Elisa was a very hyper child, and grew up not knowing she had bipolar disorder. She explained to me that when she was a teenager up until very recently, she was known for being unpredictable and very hard to get along with. Someone would not have known this just by looking at her.

Elisa is very active in her school, church, and community. She is currently running a campaign called "Say it Out Loud" which is for people who have an invisible disorder. The purpose of it is to realize that you can't just live inside your head; expressing your thoughts and emotions is very important when dealing with a mental disability. She is also very active at NIU, and currently working on her degree for counseling. She believes if she can make someone understand that they aren't alone, and that it's okay to feel the way they do. Elisa, very recently, had been through some life changing situations and doesn't want anyone else to feel the way she did.

After years of what she describes as "moody", Elisa wanted to end her life. She was self-medicating herself and one night she took a bottle of about 60 pills and downed them with a bottle of vodka. She then continued to cut herself all over her body with a pair scissors. It was at this point when her phone rang. She doesn't know why, but she answered it. It was a friend of hers from long ago, and instantly Elisa's friend knew something was wrong and called 911. The police knocked down her door and Elisa was then hospitalized. From there, she continued getting treatment for her bipolar disorder. Every day is a constant battle of not wanting to hide underneath the covers and to get up and fight to live.

Bipolar disorder isn't the only thing Elisa has to deal with. She is currently in and out of the hospital for gastric-intestinal problems, dizzy spells, and numbness on the right side her body. The doctors are assuming they are all related, but its difficult having a mental disability along with physical pain and not knowing what the problem is. Elisa explained that every day, she has to get up and plaster a smile on her face and stay active so her disability and the pain in her body won't keep her down.

When asked about her accommodations, Elisa doesn't really use any. She can get her work done just as fast as others, and still manage to get A's in her classes. There was one instance when she had to miss class to see a doctor, but her professor understood after Elisa explained the situation. I then asked about her job and if anyone knew, and her response was that there wasn't a reason to tell anyone about her bipolar disorder – especially because it's not easy to bring up that topic. But because of hospital visits, her coworkers know about her stomach problems and dizzy spells. And she gets the support needed.

As we were wrapping things up, I asked if she had anything to say to people who have disabilities. To have gratitude and to find happiness in what you have is a very important characteristic to possess. She could have taken her own life a few years ago, but instead decided on answering her phone. She could not be in the place where she is now, but she's fighting every day to live her life because she doesn't want it any other way. She wouldn't change her disability because it's a part of who she is, and it's made her into the person she is today. Elisa had a lot of important information to tell, and I'm thankful she shared her story with me."

Although very thankful for her openness, I could not help but feel very weighed down after leaving the interview. Elisa had been through so much, and she is fighting for her life every single day. It is not that she can take a magic pill and feel as if nothing is wrong. She had said to me during the interview that every single morning she struggles to get out bed. If she had a choice whether to go in to work or not, she would choose to stay in bed. Elisa has to physically will herself get out of bed and start that day's tasks. One can tell that her will to live definitely overpowers her will to let go.

What most people don't realize is that many others have to do the same thing. Fighting depression or any other invisible disability is an on-going process. Majority of the time, there

isn't a "magic potion" to cure everything. There's counseling and numerous prescriptions that help, but in no way is that a cure. It also isn't just something that people do to get attention. No one wants to be depressed and have thoughts of suicide. No one wants to be known as "insane" because they hear voices that are not there. What people with disabilities go through can be a struggle.

I would have liked to interview someone with a physical disability, but unfortunately I was unable to. But I do know from experience with my brother that it isn't a charmed life. Not everything is easily accessible for him, or many others. Restrooms, vehicles, doors, stairs without ramps are just a few examples of things that are not constructed with the idea of universal design. Universal design includes things that are automatic, or ramps for people using wheelchairs, or captions in movies for people who are hard of hearing. Combine these hassles with all of the name calling, assuming, and negative stigmatization that goes along with disabilities makes for a really tough time.

But one thing that I found very interesting is that not a single person I have talked to would change their disability. It has made them into who they are and shaped their lives. It has taught them many lessons, some of which they would not have otherwise learned. For Kalenna, she learned not to take anything for granted and to treat every day like a gift. For Elisa, she learned that if you fight hard enough to get what you want, it will be worth it.

When helping with this documentary project, I've learned a lot about myself and others and I feel like most Capstone or research projects don't do that. I may not have done studies and conducted experiments, but I learned about two extremely wonderful people and will forever remember them as an inspiration. I feel very privileged to be given this opportunity and am very fortunate to have met them.